37

Link

March/April 1975 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)

Link No. 37

Association for Spina Bifida & Hydrocephalus (ASBAH)

Patron:
HRH The
Duchess of Gloucester

Chairman:
Mr. R. B. Zachary, FRCS
Hon. Treasurer:
Mr. E. S. Gower, FICS, FHA

Correspondence to ASBAH
at the National Office:

Devonshire Street House,
30 Devonshire Street,
London W1N 2EB
Tel: 01-486 6100 or
01-935 9060

General Secretary:
Miss M. E. Oughtred
Appeals Secretary:
Mrs. Kate White
Liaison Officer:
Mr. H. D. Macfarlane
Appliance Officer:
Miss F. A. Birkett
Link Editor:
Mrs. Susan Gearing

Editorial

By the time this issue of *Link* is in your hands, spina bifida and hydrocephalus will have been "in the news" through the B.B.C. programmes in the week of 24th February. Reaction will vary according to many factors, personal experiences, hopes and fears; and attitudes formed by environment, faith and thought.

It is therefore wisdom and not lack of concern which guides the Association for Spina Bifida and Hydrocephalus to the view that care of the individual is its raison d'etre, and that it is not its role to have a policy about methods of treatment — only that the best decisions be made, as far as humanly possible, in each and every case.

It is said often by people in many fields that there is no such thing as unhelpful publicity. It is up to us who are *Link* readers, and as such involved people, to make the most of the opportunity to see that an ever wider public know of our work, of the tasks which lie to our hand in helping our members to the greatest possible fulfilment in life.

Not unnaturally, as ASBAH is only nine years old, contacts with those who were adult or in their teens nine years ago are not as many as with younger members and their families. *Link* serves to help the parents of infants and young children, but *Link* is for *all* members and articles or letters from older members will be very welcome and will give encouragement, interest and ideas to those still at school.

Our next issue will carry a report of the Conference at Owens Park, Manchester, with its theme of Hobbies and Interests — a most important aspect of life for us all, whether handicapped or able-bodied.

Contents

FRONT COVER: ASBAH's Patron, HRH The Duchess of Gloucester talks to Dr. J. Lorber, MD, FRCP, at the Dorchester Ball. Photo Barry Swaebe.
Fuller report on the Ball appears on Page 14.

Something borrowed something new!

Toy libraries are bringing fun and enjoyment into the lives of many handicapped children and there are now 130 toy libraries in this country, with over 100 more in the planning stages. Some toy libraries are based on clinics, hospitals and assessment centres where the loaning of toys will be closely linked to the therapy the child is receiving at the centre.

Community based toy libraries however, bring more than toys into the lives of handicapped children and their families as they give opportunities for families to meet at local level and many community toy libraries develop "spin off" activities such as baby sitting, picnics, parties, cooking sessions, carpentry sessions and arts and crafts activities.

The toys for toy libraries are in the main chosen from the ranges of well known manufacturers such as Abbatt, Galt, Fisher Price and Kiddicraft and the Toy Libraries Association has several helpful publications to guide toy library organisers in their choice. Sometimes toys are adapted for one particular child — the Leicester toy library converted a battery operated car from foot to hand controls for a small boy with spina bifida. The extra support needed was devised with the help of the boy's own therapist. One rather lonely and isolated youngster became the envy of his neighbours as he sallied out in his own independent transport!

Some toy libraries also make special items for their stocks— usually items that are not available commercially or which need to be "sized up", for a common problem with handicapped children is that their physical age is beyond their developmental stage and so, for example, a giant hammer peg toy will be needed for an older child or adult as the ones available in the shops are designed for the size and strength of a 2-5 year old.

by

MRS. LESLEY MORELAND
Director of the Toy Libraries Association.

Community based toy libraries are open to all handicapped children and their families. This is a very important aspect of toy libraries as it means that families with a handicapped member with a rare handicap have the chance to meet and give supportive help to each other and also that the many children whose handicaps have not been precisely diagnosed can be helped from the very earliest age. Most toy libraries have customers from birth to adulthood.

Wide acceptance is now given to the promise that children should be stimulated through play from an early age so that they can reach their full potential. How much more important this is for handicapped children, who will need every help to develop their resources, have a shorter attention span often and therefore need more toys than the average child to provide the variety and quantity needed. The toy library can help greatly by providing access to a wide range of toys, enabling parents to try before buying so avoiding expensive mistakes and also giving the child the chance to play with many more toys than most families could afford.

Some questions often asked are:

Do toy libraries charge?

Some toy libraries do make a small charge — say 5p per month per toy — this is partly to help funds but more importantly to reassure parents that should an accident happen with a toy then the kitty is already there for repair or replacement. Breakages do occur but often these are the result of use by other members of the family circle — one classic example was the scooter that was returned only 6" in height;

Continued on p. 11

Health matters

When asked to write on bowel training, my initial response was that "my" children also had bowel problems which I could not solve, so what had I got to say, but I have been persuaded that my failures might well encourage mothers battling with the same problems.

Many children with spina bifida have no serious bowel problems. They will, if potted regularly at the same time each day, have a bowel action either once or twice a day almost or quite normally. So we will consider those with a bigger problem.

BOWELS

Barbara Webster SRN RSCN
Matron, Hart's Leap Cheshire
Home for children.

There are several points that should be borne in mind.

1. The position in which the child sits on the toilet or pot has a lot to do with the ease with which he evacuates his bowel. That is why he needs to sit on the toilet and not just be allowed to soil his pants or nappy.

2. Consider how you yourself sit on the toilet and then note whether your child adopts this position or whether he merely balances across the top of the toilet or pot with his calipers restricting him.

3. It generally doesn't matter if the child does not have his bowels opened every day. It can still be normal providing:

a) when he does have a motion it is not excessively hard, or dry or 'rabbity'.

b) when he does go he has a reasonably large stool.

c) the stools do not contain blood.

d) he does have a motion three times a week.

4. Diet. Before resorting to aperients, suppositories or enemata, consider his diet. Some foods tend to make certain children's stools looser and some tend to make them more constipated, so regulation of the diet may well be adequate. Temporary loss of control is often due to an error in diet e.g. over-eating or change of food at Christmas.

The children with a bowel problem can be divided into:—

(a) *Those who have normal stools but are unreliable in time.* These may be helped by the use of suppositories to cause evacuation at a certain convenient time each day. When an action is reliably obtained with suppositories and with no soiling in between, it can be considered acceptable control.

(b) *Those with constipated hard stools.* These stools are much easier to clean up and they smell less. The use of aperients or suppositories may regulate the consistency of stools. Trial and error is the only way to ascertain the most effective aperient and the correct dosage and frequency of use. Try only one substance at a time and don't expect instant results. If after two weeks there is no change for the better you should try another. If the stools become too loose, use less and if motions are too frequent use less often. If constipation persists give a larger dose or the same dose more frequently.

(c) *Those with loose or frequent stools.* First exclude constipation with overflow, which is far more likely than anything else. Almost all children I know who have presented with loose stools have already been grossly constipated with bowels overflowing. This gross constipation may need fairly drastic enemata or suppositories to clear it up first, before proper control can be established.
Loose stools make the child's bottom sore, are far more messy to clean up, stain napkins and clothes and spread the aroma around, but at least may keep the bowel half empty. If regulation of the diet fails to control these, an anti-diarrhoeal drug may be beneficial.

Constipation is the most important of the bowel

Continued on p. 7.

Local Association News

Now—the Fun Bug

Derby. The Association has found two good friends (left) Mr E. Gillibrand and Mr J. Lawes, Engineering lecturers at Derby Technical College. With the help of members of the Association they designed Fun Bugs — battery operated vehicles. For further information contact Derby Association.

Tricycle made by two

Below— five-year-old James Mitchell of West Hagbourne near Didcot with his special new tricycle and its inventors, Peter Evans (left) and Jeremy Stroud, Pupils of St Birinus Comprehensive School. The boys spent five months cleaning up and substantially adapting a rusted old tricycle given to them by a cycle supermarket in Thatcham. It can now be hand-operated. Total cost of adapting the bike— £5. Photo: Mike Hayward, *Evening Post, Reading.*

THE SHASBAH TROLLEY
FOR HANDICAPPED CHILDREN
Patent applied for in
UK, Commonwealth Countries, USA, Canada

Standard model for children one to five years old costs £11.00 plus carriage.

Large model for children five to ten years old costs £14.50 plus carriage. Overseas prices on application.

Produced by **Southampton and District Spina Bifida and Hydrocephalus Association**

All enquiries to: Mrs. K. Charrett, 46 Tillbrook Road, Regents Park, Southampton.

Local Association News

On target

Left—young archer, Steven Tapp, 9½ years, who lives in Old Stratford, near Newport Pagnell. Steven is the only handicapped member of the Newport Pagnell Archery Club and he took part in the Club Championships at the end of last year. This was Steven's first competition. The seven boys in his class (under 11 years) shot a Sherwood Round—72 arrows at 20 metres—and Steven with a score of 466 won the Gold Medal, which he is wearing in the picture.

Law's on our side

Staines and Hounslow. The Metropolitan Police have presented this Association with a cheque for £1,000 as the result of a special Charity Boxing Dinner. A special attraction of the evening was an auction of unique sporting items—a pair of boxing gloves signed by Muhammad Ali, and another pair signed by John Conteh, a football signed by the England team, and a rugby ball signed by the All Blacks and the Barbarians rugby teams. The evening organised by 'T' Division (Metropolitan Police) Athletic and Social Club, raised a total of £2,000 for Staines and Hounslow Association and two other voluntary organisations.

BOWEL TRAINING: *Contd. from p. 5.*

problems. A grossly constipated child has a build up of pressure in the abdomen, may complain of headaches and may vomit. Occasionally children are admitted to hospital suspected of a blocked valve when really they are just very constipated, often with overflow. Mother will say that the child has been to the toilet properly or has loose stools which may be misleading, and once the child has been cleared out there is a dramatic improvement.

The psychological state of both mother and child to bowel care is very important. If mother is over-anxious, then the child will also be over-anxious, but if the mother can treat this as a problem which affects both handicapped and normal children and they are both relaxed, a better result will be obtained.

I have one child who, although not requiring suppositories or aperients, does need stimulating on her anal sphincter. We do this by putting on a finger cot and inserting approximately 1 to 1½" of an index finger into her rectum. We feel her sphincter twitching and if we then sit her on the toilet she will have an adequate bowel action. We find she will not have a bowel action of her own accord if this is not done every day.

Collection of stools. Children who are toilet-trained or who wear a urinary appliance should not need to wear a napkin to collect the stools and the mother should not need to wash napkins at this stage. A fairly tight fitting pair of pants containing half a disposable nappy tucked inside is generally adequate, Nylon pants are most suitable as they stretch and mould well and allow the pad to be changed without removing the calipers or pants. Alternatively, pants of either cotton net or stretch nylon material, opening down the side seams with velcro or press studs added for closure, allow easy changes of pad. With urinary appliances it may be necessary to make a hole for the bag to hang through, so that it is not squashed up in the firmly fitting pants.

A MUM’ EYE VIEW

PART 2

A Mum’s eye view. This is the second part of Mrs Ursula Emmanuel’s very personal account of her experiences in coping with a family which includes a fairly handicapped spina bifida child.

When Cheryl was about six months old, we had an unexpected jolt. An article appeared in our local paper about a young mother with a year old daughter with spina bifida and hydrocephalus, asking mothers in a similar position to get in touch with her about mutual problems.

My first reaction was one of recoil, I felt we had overcome the worst time and I wanted to leave well alone. Then I began to think that perhaps we could help. Just to look at Cheryl one could see she was a lovely intelligent happy baby, even if she had problems and this alone would cheer a mother who had just had a baby with spina bifida. So in the end I went along to meet the other mother and a few others who had seen the article. This was a turning point in my life because from this informal meeting a local branch of the spina bifida association was formed, with the help of the Lions Club, whose members gave their energetic help. We held our first public meeting in March 1968, addressed by a Consultant Surgeon from the Hospital for Sick Children, Great Ormond St, London. Films were shown, which so upset one well-known local man that he fainted. The films pulled no punches and so brought home to people with no previous knowledge just how serious a problem this is.

Cheryl was a year old then and we had a beautiful photograph taken showing her bright and smiling. We wanted to say “Look at this lovely child, she could be yours—But she has problems. She may never walk, won’t you help her?”. I must add that since then I have never used photographs of Cheryl for publicity purposes, as I feel that, as children get older, publicity is not good for them.

The aims of spina bifida associations are similar but in Jersey we have special problems as we do not come under the National Health Service and so the family has the extra financial burden of having to pay for calipers, and other essential appliances and treatment. The Association’s funds are therefore largely used in helping with these expenses and with the costs involved when a child goes to the Mainland for treatment.

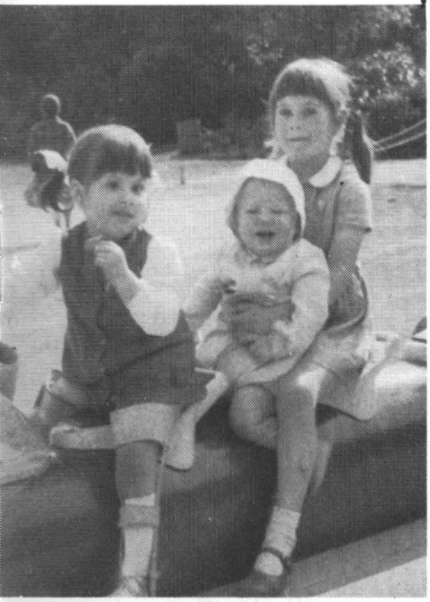
I’m sure most mothers would agree that the Association’s most important role is that of giving moral support to parents, to be there to listen and to help with information.

One of the main headaches for some families is to find they are unable to “get through” to doctors to get the information they badly need. The young mother with a new baby is worried by the brisk “hurry-along-please” atmosphere of some hospital clinics. We know the doctors and consultants are terribly busy, cannot get too involved with emotional mothers and sometimes honestly don’t know the answers to all our questions —but it does help to feel they care and that they have told us all they possibly can.

Whilst most Local Authorities and hospitals are happy to work with the Spina Bifida Association in helping families, I feel the most important thing is the attitude adopted by the parents themselves. This often determines the reception they get from the authorities. To be confronted with a parent who is obviously itching to start thumping the table and demanding his rights is bound to start things off on the wrong basis, whereas parents who present a calm appearance, who show due respects coupled with the expectation that their questions will be treated with consideration, will obviously create a better impression and so receive more help.

I find it a good idea to make a note of all my queries and produce this when I see the consultant. It may make him laugh but this helps to break the ice — and you don’t

S



Cheryl, aged three years, very much in the saddle while Lindsay, aged four, takes on the task of looking after the Emmanuel's adopted son Nicholas, aged one.

forget all you wanted to ask and come away none the wiser!

other children

My most immediate concern after Cheryl was born, was for my other little girl, Lindsay, then aged two and a half and the effect of having a handicapped sister on her life and her childhood. And I vowed I would do everything possible to ensure that she would not suffer. Of course she would be affected — we are a family and each member is linked to the others. I saw the dangers and how without meaning to, one could centre one's attention on the handicapped child and the older child would feel pushed into the background.

So right from the beginning, we tended to put Lindsay first, although of course Cheryl's medical requirements were never ignored — we never made them seem important to Lindsay, just one of those things we had to do.

I think this attitude helps the handicapped child too. It is very bad for *any* child to be the centre of attention and have its every wish made much of. So we tried to treat Cheryl as "more normal than normal" to counteract the effect of the special attention and treatment she needed.

I must say that I feel very strongly that medical problems — or any other problems for that matter — should not be discussed in front of the child or the other children in the family *ever*. We have tried to make this a firm rule, even before Cheryl could understand — it clearly could become a habit. I have seen older children either deeply embarrassed at having their personal problems discussed, or, having been subjected to this practice from infancy, they develop into hypocondriacs and then problems assume far greater proportions than they should — so even at the risk of seeming slightly rude to well meaning friends, do discourage discussion in front of the children — you can explain later. It is also a good idea to establish the practice of a short private talk with the doctor or consultant, so avoiding the need to ask questions in front of the child which could cause unnecessary worry.

When Cheryl was about 18 months old, I began to feel desperately in need of another baby. I felt cheated out of Cheryl's babyhood, the first two months in hospital and the ensuing months fraught with anxiety. But we felt very strongly, in view of the risks which the statistics showed, that it would be wrong to bring another child into the world — This is a purely personal view — parents must take advice and make up their own minds.

On the other hand we felt that another child would balance the family and that a normal brother or sister would help Lindsay and take the limelight off Cheryl — and of course we ourselves wanted another child, to whom we felt we could give a good life. So, after a lot of consideration, we decided to apply to adopt a baby boy.

We were very lucky and only six months after our application was approved we were told about Nicholas, and we fetched him home on 25th July 1969, my thirtieth birthday, when he was two months old.

We have never regretted our decision and Nicholas is as much ours as the girls. He is growing up very close to Cheryl and they are great company for each other.

There is of course a very big BUT — it is *very hard work*, having another baby when you have a handicapped child. The washing, the lifting

Continued on p. 14.

Family page

Puppets—excitement at your fingertips

by JANET DALGLISH
Director, The Leisure Centre.

SPINNING DANCER.

POP UP PUPPET.

When your movement is rather limited it is fun to be able to make all sorts of exciting things happen. With a puppet in your hands you can dance or fight or disappear, you can be any age or from any country, even a dragon or a creature from outer space. With pop-up rod puppets you can creep up slowly or leap out with a rush. Tiny finger puppets turn into a whole family on your hand and an army can appear in one bit of cardboard behind the shadow show screen. One person can produce a show on their own, or a group can produce several items, as well as posters, programmes and music. Shy people often blossom, when they are hidden behind the screen, quiet voices have to be projected loudly, slow fingers to move with more agility. People who cannot play many team games may enjoy the team work involved in a show, perhaps as a piece of community service.

Possible puppets can be found anywhere, look for matchboxes and sweet packets, plastic containers and cereal boxes, old umbrellas and worn out brushes, odd gloves and socks. You will also need scraps of paper and material, oddments of wood, buttons and tops from bottles and tooth paste tubes, as well as glue and scissors. The matchboxes will need faces of paper and wool hair to turn them into 'two-faced' finger puppets. You can drape a square of material, soft paper or hankie over your hand for clothes, poke out a thumb and third finger for arms and your puppet comes to life.

Try a paper bag or long envelope with a hole for a mouth so you can push a finger through for a rude tongue, or an elephant's trunk. Two holes at knee level in a flat bit of card will make a dancer—you can even add boots or ballet slippers in felt or card. The old socks and stockings can have button eyes and nose and a felt tongue with multi-coloured patch to make a snake, or ears and tail for a monkey or pig. Put your thumb in the heel and fingers where the toes go for an open and shut mouth, that is liable to say some surprising things. Old brushes need paint to turn into animals such as porcupines or clowns.

Old chair back struts or umbrellas will produce rods to make pop-up puppets or spinning dancers. Use a small tin, a round wooden ball, (from carpenter's shops) or stuff a circle of material, to make the head. Glue and tack it to the rod, (make a hole in the wooden one). For the pop-up find a tin large enough to take the head easily and make a hole in the bottom with a crown cork opener, to fit the rod easily. Make a dress to reach from the neck almost to the bottom of the rod and to fit the tin. Add loose arms and hands, sew or glue dress to the neck of the rod. Glue the outside of the tin and slip it up the rod, with the open side to the head, leave room to hold the rod below the tin, then press the dress round the tin. When it is dry you can see if your pop-up character will creep up and look round at you or rush up from the tin to scare you.

Dancers begin in the same way with a nead fixed to the rod, but then you use a smaller tin with the hole at the top and the open side down, making sure the hole is large enough for the rod to move easily. Slide up the rod till it makes the body and put a bit of foam, a twist of string or paper inside to stop the tin slipping. Dress the doll elegantly, with a wide skirt and petticoats and then she will spin round on the rod with a little circular movement of your hand.

For further ideas look in your public library, which can also produce folk songs and stories for plays; or write to us at: The Leisure Centre, 225 Walworth Road London SE17.

The Leisure Centre is a charity offering help to individuals and groups concerned with play. It concentrates on children aged 3-14, especially the handicapped or deprived. Training sessions are arranged, and the membership scheme offers a wide range of pamphlets, opportunities to borrow books, pictures, samples and discussion kits, and a chance to consult an experienced leader.

Something borrowed:

Contd. from p. 4.

Dad had backed his car over it! Sensible choice of toys can avoid many problems in this area and some toy libraries have a special table of 'tough toys'.

Do the children find it hard to bring the toys back?

For most children, a new toy is very exciting but by the time they have had it at home for a month, the novelty begins to wane and the prospect of borrowing another toy makes parting with the first toy bearable. Toy libraries do not stock 'personal' toys such as teddy bears and cuddly dolls as these toys need to be owned personally as an emotional attachment is formed.

How is hygiene maintained?

As toys are returned to a toy library session — rate of meetings vary but twice a month is typical — these are set aside and at the end of the session the organisers will wash and check toys for damage of missing parts. It is very important that the toys are clean and attractive for no one wants to borrow a tatty toy. Many toy libraries have back up teams of people — fire brigades, local schools etc. to repair and paint toys as well as to make them.

Who can be a toy library organiser?

Very many backgrounds are found among toy library organisers — parents of handicapped children, Red Cross groups, community groups, church groups, etc. and also at the professional toy libraries a varied selection of disciplines are represented — occupational therapists, physiotherapists, speech therapists, psychologists, doctors, social workers. Most toy libraries have both voluntary and professional people involved and both categories have found helpful the chance to meet in a neutral setting.

The Toy Libraries Association

The Toy Libraries Association was registered as a charity in 1972 to become the central organisation for toy libraries and from the spring of 1975 will have a permanent exhibition of toys for toy libraries in its new premises. The first toy library, started by Mrs. Jill Norris in Enfield opened in 1967 and it is largely due to her inspiration and energy that toy libraries have spread so quickly.

If you would like to have details of TLA publications, an address list of toy libraries and details of the work of the Association we would be very pleased to send you these; if your local ASBAH group would like to consider starting a toy library in your area, we would be even more delighted to hear from you and to help you in any way we can.

Please write to: Toy Libraries Association, Sunley House, 10 Gunthorpe Street London E1 7RW.

Aids and equipment

Never mind the weather - here's how to keep out the . . . RAIN

If you have a Baby Buggy or Major Buggy the best thing to have is the raincape made by *Simplantex.* This keeps both your child and the Buggy dry and is made from strong waterproof non-tear nylon. It can also be worn by a child sitting on the top of a large pram in a pramseat, or in any type of pushchair. The Baby Buggy Cape costs £1.95 and the Major Buggy Cape £3.53 and they are stocked by many shops and stores and are also available by post direct from *Simplantex Ltd.,* Willowfield Road, Eastbourne, Sussex.

The same firm also supply the "Wheelymac" which is similar to the Cape but fits over an adult size wheelchair and costs £4.08. The Major Buggy Cape will fit a junior wheelchair. The only snag here is that the occupant of the wheelchair cannot himself wheel as his hands and arms are inside the cape! One method of protecting yourself from the elements if you are an adult or a teenager in a wheelchair is to wear an anorak and a waterproof "apron". *Simplantex* make one which encases your legs and covers you up to the waist and fits neatly over the arms and side of your wheelchair. This costs £2.59.

. . . And the cold


Apron for wheelchair

A "Comfy - Cover" is ideal for keeping your legs warm in a wheelchair and it is also showerproof. It is made of double thickness quilted nylon with a non-rust zip down the centre so that it opens flat onto the seat of the wheelchair but forms a bag round your legs. These are available in navy blue in hip sizes 30"-40" for £6.00 and 44"-62" for £6.50 from *Comfy Products,* Comfort House, Marshall Avenue, Bridlington, Yorks. When ordering state your normal hip measurement plus 4" to allow room for outdoor clothing, your height, and the width of the wheelchair back between the handles.

Simplantex stock a "Cosysit" which is a foam wheelchair interior made of showerproof quilted nylon & lined with tartan. It has a full length zip and there is a junior model for £5.27 and an adult model for £7.37.

For babies in prams or push chairs Babynests are very useful. These are sleeping bags filled with terylene and covered with cotton, nylon seersucker, tricel, fur fabric or showerproof quilted nylon. They have two full length zips to make nappy changing easy and some have an adjustable cord round the head piece and carrying handles. They are made by *Simplantex* and *Mothercare* and cost from £5.00 to £6.00. The same firms also make Prambysits or Cosy toes which are similar to the Babynests but leave the toddlers arms free, enclosing their legs in a warm bag. *Mothercare* have one with two legs instead of a bag which is useful if you have a pushchair with a dividing front centre strap. These cost from £4.00-£5.00 approx.

Mothercare products are available by post from Cherry Tree Road, Watford, WD2 5SH, Herts as well as from their retail shops.

Wheelchair covers: A member of the North East Association wrote to me recommending another firm making wheelchair covers, similar to those made by *Comfy Products.*

The firm is: S & E Southern (Textiles) Ltd, 100 Pans Castle, Tow Law, Bishop Auckland, Co. Durham.

Aids and equipment

USEFUL BOOKS ON CLOTHING

1) *Clothing for the Spina Bifida Child.*

This very useful booklet written by Barbara Webster, SRN RSCN is published by ASBAH and costs 15p from National Office . It covers all types of suitable clothing, and there are suggestions for simple alterations to garments.

2) *Comfortable Clothes.*

This is a free mail order catalogue of easy to wear garments for those with special needs and is published by the *Shirley Institute,* Didsbury, Manchester, M20 8RX on behalf of the suppliers of the garments. Most of the clothes are for adults, there is a page on incontinence pants, and the Wheelymac cape by *Simplantex* is included.

3) *Section 2 of Equipment for the Disabled Clothing & Dressing for Adults.*

This book covers a large range of clothing suitable for a variety of disabilities including incontinence. It includes many suggestions for adaptations to clothing to enable the handicapped person to be independent with dressing. Stockists and approx prices are quoted.

This is available from 2 Foredown Drive, Portslade, Sussex, BN4 2BB and costs £1.05.

4) *Clothing for the Handicapped child.*

This is very similar to the above publication and considers all types of clothing for the handicapped child. It contains chapters on "Aids to independence", "Individual adaptions" and the "Principles of selecting clothing". Many of the ideas are not applicable to Spina Bifida as this book is intended to cover many different handicaps.

This is published by the *Disabled Living Foundation,* 346, Kensington High St, London W14 at a cost of £1.20.

The *Disabled Living Foundation* also publish a book called *Clothes Sense* (for handicapped adults of all ages) and several other books and information sheets on clothing.

These include *Sewing Notes* which gives advice on how to adapt existing clothing for the disabled and costs 50p; *Dressmaking for the Disabled* which shows how to adapt paper patterns for individual *Clothing and Incontinence* (8p); *Clothing and the Incontinent Older Child* (8p); *Protective Garments* (15p); *Clothing for Wheelchair Users* made by *Comfy Products.* (20p).

CAT SUITS

Trousers can be a problem for children who are prone to back sores as so often the elastic at the waist rubs across the scars. Catsuits are the answer to this problem for the children under 6 or 7 years, but are not available for older children. A small manufacturing firm in Yorkshire may be prepared to make catsuits in larger sizes but they need to know what the demand would be. If you would be interested in this project, please let me know so that I can get some idea of numbers.

I appreciate that catsuits are not the answer for everyone and that many will still be left with a trouser problem. In this case Mrs Margery Thornton, the clothing adviser to the *Disabled Living Foundation,* **would be most interested to hear from you. She would like to know of your experiences with clothing problems and any solutions to such problems. The Foundation at 346 Kensington High Street, London W14 carries out continuous research into the problems of clothing for the Disabled.**

SOCKS

White cotton ankle socks are still available from the National Office, in sizes, from 7 to 10 i.e. shoe sizes 9 (childs) up to 6 (adults). The cost is 11p per pair up to shoe size 1 ½ and 15p per pair for shoe sizes 2-6. Please send orders to Miss Felicity Birkett.

Appeals and publicity

Doncaster to the Dorchester

The last two months have been pretty hectic what with the Christmas appeal, Christmas cards, carol singing etc etc, acknowledging the very satisfactory response to the 10,000 letters we sent out, attending the Pigeon Show and organising the Midwinter Ball.

The Pigeon Show was, as before, staged in the Betting Hall at Doncaster Racecourse on 17 and 18 January and it is estimated 10,000 people attended. Valuable birds were donated for the auction and it is expected ASBAH will receive a cheque for upwards of £4,000.

We are greatly indebted to Tim and Olga Murphy, of Don and Dearne ASBAH, without whose splendid help we could not have coped. They, my husband and I were on the go non-stop, selling fundraising items and handing out literature. The warm sympathy and interest shown by the pigeon fanciers was most encouraging and we feel we have really firm friends amongst them.

Tim Murphy is a super-salesman and ran a very successful variation of the lucky "brick in the wall" game using spina bifida ballpoint pens — I'm sure he'd be pleased to send instructions if you want to try it.

From Doncaster to the Dorchester Hotel for the Midwinter Ball. We were greatly honoured by the attendance of HRH The Duchess of Gloucester and charmed by her very friendly, gracious and informal friendliness. Over 700 people attended the Ball and supported the tombola, bingo etc so enthusiastically that we expect a profit on the evening of £7,000. It is indeed good of people to be so generous.

Our picture shows the Duchess presenting to Mrs David Page — the wife of the sponsor of the Ball — a token of our gratitude.

With the proceeds of the Ball, donations from Local Associations totalling £3,975 to date, other generous gifts given or promised, we have nearly £50,000 towards the Short Term Care appeal, plus, we hope, about £15,000 to come from efforts being organised by the Independant Order of Foresters. Still a long way to go, but a good start. I was hoping that all of their £20,000 pledge would be embarked for Short Term Care but in some areas the money is being used locally so we can't have it both ways!

The Appeals Committee has now been asked to raise £17,000 for two important research projects, to improve mobility appliances and toilet facilities, so if you have any millionaires in your district interested in good causes I'd like to meet them!

KATE WHITE

A MUM'S EYE VIEW:

and the carrying alone make big physical demands. I couldn't have managed it without a helpful husband, who never grumbled if his meals weren't on time! Being able to drive helped a lot and thank goodness I have reasonably good health.

So I would advise any one thinking about this particular question to think very hard before reaching a decision — there is a lot to consider. But if you do decide to have another baby, either your own or by adoption, it is the most wonderful thing to have a normal baby to love and watch grow and develop without anxiety, after the worry attached to all spina bifida babies, much as one loves them too.

Continued in the next issue of *Link*

ASBAH publications and publicity

Your Child with Spina Bifida, 3rd Ed., by Dr. J. Lorber, MD, FRCP	20p
Your Child with Hydrocephalus by Dr. J. Lorber, MD, FRCP	15p
Equipment & Aids to Mobility by O. R. Nettles, MCSP, ONC. A folder of four booklets	complete set 25p
Clothing for the Spina Bifida Child by Barbara Webster, SRN, RSCN.	15p
The Nursery Years, by Simon Haskell, M.A., Ph.D., and Margaret Paull, Dip. Ph.H.	15p
Information leaflets	100 for £1

All available from: ASBAH, 30 Devonshire Street, London W1N 2EB. (Special rates available to Local Associations.)

Scottish Spina Bifida Association booklets

The Spina Bifida Baby by O. R. Nettles, MCSP, ONC	10p
Growing Up with Spina Bifida by O. R. Nettles, MCSP, ONC.	20p

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh, EH4 2BW (at special rates for bulk orders).

Posters. Double Crown, 5p each, "Future Bright", 10 for 20p.
Flag Day emblems. 1,000 for 50p.
Cards for notice boards. 10 for 10p.
Car stickers. 5p each. Postage extra.
Fund-raising items. Price list/details on request.

Handling the Handicapped

This book is an excellent guide for the handicapped person, his relatives and friends as well as for professional people concerned with the lifting and moving of the handicapped.

The text is well illustrated and there are several suggestions about how the handicapped person can help himself as well as chapters concerned with the choice and use of hoists, beds and wheelchairs. The problems of handling disabled people when swimming and horse riding are also discussed. This book should be read by teenagers, youngsters and parents.
Published by Woodhead - Faulkner Ltd, Rose Crescent, Cambridge CB2 3LL.

Holidays for the physically Handicapped

This popular guide book, published by the Central Council for the Disabled, completely sold out last year, so be sure to get your 1975 copy as quickly as possible. Cash with order please. The book costs 20p and postage and packing is 30p. CCD, 31 Eccleston Square, London SW1V 1PE.

The list of PHAB courses for 1975 is now available. Write (S.A.E.) or phone for your free copy to: PHAB Office, Devonshire St, London WIN 2AP. Tel: 01-935-2941.

Local Association offers

Badges. Silver and green enamel with pin fastening. Replica of the Spina Bifida emblem. Bulk orders welcomed particularly. Price: 22p per badge. Postage extra. (For a single badge please enclose s.a.e.) Apply to: Mr. K. McKenzie, Badges Secretary, Salisbury & District ASBAH, 111 East Gomeldon Road, Gomeldon, Salisbury SB4 6LZ.

Badges for children. Good quality 1¼in diam. SB symbol and the words, "Spina Bifida Children" in black on green background. Price: 25 badges for 75p; 50 for £1.40; 100 for £2.65, including postage. Cheques and postal orders crossed and payable to "SASBAH". Send with order to: Mrs. I. Olditch, High Lea, Turners Green Lane, Wadhurst, Sx.

Ties. Heavy weave washable terylene with SB symbol on dark blue *or* dark green. Sold by N. Hants, S. Berks and W. Surrey ASBAH. Price £1.10p plus postage, while stocks last. Reductions for bulk orders. Cash with order to Mr. B. High, 10 Woodruff Ave., Burpham, Guildford, Surrey. Please state colour.

Inter-association holiday opportunities

Camber Sands, nr. Rye, Sussex. New, well-equipped chalet, on pleasant situation near the sea available for families with spina bifida members. Sleeps six. Please apply to Mr. S. Evans, 1 Coniston Gardens, Wembley, Middx. 01-904 7840.

Great Yarmouth. Self-contained 6-berth caravan at Caister Beach Caravan Camp, nr Gt. Yarmouth. Details from Mrs. E. N. Barefoot, 23 Marlborough Road, Southall, Middx. Tel. 01-574 5067.

Looe. Bungalow, two bedrooms, spacious accommodation at Millendreath Holiday Village, nr. Looe, Cornwall. Mr Keith Jackson, 202 Exeter Street, Plymouth.

Looe. Holiday bungalow at Millendreath Holiday Village. Sleeps six. Fully furnished. Further details Mrs. Cook, 19 Winslade Road, Harestock, Winchester.

Lincolnshire Association is interested in exchanging its holiday bungalow at Humberston Fitties, near Cleethorpes for one further afield. It is a three bedroom bungalow to accommodate 6-8 people. Further details from Mrs. W. Steele, 59 Louth-le-Clay, Grimsby.

Mablethorpe. Self-contained 6-berth chalet situated at Golden Sands Estates, Mablethorpe, Lincs. Apply to Mr. Ken Hall, 17 Walhouse Street, Cannock, Staffs.

New Forest. Well-equipped chalet, sleeping six people. Within easy reach of Bournemouth, Beaulieu, etc. Swimming pool, paddling pool, restaurant and playground on site. Details from Mrs. A. Rae, 16 Clifton Road, Lee-on-Solent, Hants. Tel. Lee-on-Solent 550242.

Prestatyn. 6-berth luxury San Capelle caravan situated at the Bourne Leisure Centre, Bastion Road, Prestatyn, North Wales. Bookings to Liverpool Association, 46 Manchester St., Liverpool, L1 6ER. Tel. 051-236 4732.

Selsey. New well-appointed, self-contained 16ft. x 30ft. 6-berth mobile for families with spina bifida members. Sited at Selsey, Sussex. For full details please send s.a.e. to Mr. R. V. Taylor, 20 Orchard Road, Horsham, Sussex. Vacancies before 24th May & after 20th Sept only. Booking for 1976 after 1st Nov 1975.

AFFILIATED ASSOCIATIONS – Hon Secretaries

BEDFORD AND DISTRICT
Mrs. A. Merry,
12 Crofton Close, Bedford.

BOLTON AND BURY
Mrs. B. Grosvenor,
12 St. Peter's Road,
Bury, Lancs, BL9 9RB.

BOURNEMOUTH, CHRISTCHURCH & DISTRICT
Mr. D. D. Lanning.
1 Blythe Close.
Christchurch. Dorset.

BRISTOL
Mr. R. W. Mabbutt,
20 Bramble Drive,
Stoke Bishop, Bristol.

BROMLEY & DISTRICT
Mrs. J. Moore,
102 Westwood Park,
London SE23 3QH

BUCKINGHAMSHIRE
Mrs. L. E. Tilly,
2 St. John's Drive,
Windsor, Berks.

BURNLEY
Mrs. M. Robinson,
266 Colne Road,
Sough, Earby.

DARLINGTON AND DISTRICT
Mrs. D. Allan,
6 Lingfield Green,
Darlington DL1 1DD

DERBY
Mrs. P. E. Broadgate,
11 Old Lane,
Darley Abbey, Derby.

DEVON AND CORNWALL
Mr. J. Carter,
5 Culme Road,
Mannamead, Plymouth.

DON AND DEARNE
Mr. T. J. Murphy,
43 Cutts-Avenue,
Wath-On-Dearne, Yorks.

EAST ANGLIAN
Mrs. P. Symonds,
28 Leys Road, Cambridge.

ESSEX
Mr. J. T. Saunders,
2 The Ruskins, Rayne,
Braintree, Essex.

GLOUCESTERSHIRE
Mrs. B. Symonds.
9 Collum End Rise,
Leckhampton, Cheltenham

GREENWICH
Mrs. J. Goldsmith,
194 Dacre Park,
Lewisham SE13 5SH

HALIFAX AND DISTRICT
Mr. A. L. Crowther,
42 Marldon Road,
Northowran, Halifax.

HAMPSHIRE NORTH, W. SURREY & S. BERKS.
Mrs. Selby.
The Old Police Station,
Leapale Road, Guildford

HAMPSHIRE SOUTH
Mr. C. Bowen,
7 Brocklands, Havant.

HERTS AND SOUTH. BEDS.
Mrs. S. M. McGavin,
21 Claygate Avenue,
Harpenden, Herts.

HUDDERSFIELD
Mrs. C. Carter,
32 Winget Avenue,
Cowlersley, Huddersfield.

HULL & DISTRICT
Mrs. G. D. Brown,
233 Cranbrook Avenue,
Hull HU6 7TX

JERSEY (Channel Islands)
Mrs. U. Emmanuel,
La Haute Ferme,
Mont a l'Abbe, St. Helier.

KENT
Mrs. P. Fearn,
120 Mill Street, E. Malling.

LEEDS AND BRADFORD
Mr. G. Baxter,
38 Hoyle Court Road,
Baildon, Yorks.

LEICESTERSHIRE
Mr. P. Cusack,
39, Kings Walk,
Leicester. F.E.

LEIGH & DISTRICT
Mrs. S. Goulding,
20 Pendle Road,
Golborne, Lancs.

LINCOLN AND DISTRICT
Mrs. P. Keyse,
Pinfold, Chapel Lane,
North Scarle, Lincoln.

LINCOLNSHIRE
Mrs. Blakey,
8 Shetland Way,
Immingham,
S. Humberside

LIVERPOOL
Mr. P. A. Glennon,
LASBAH,
46 Manchester Street,
Liverpool, 1

LONDON
Mr. J. Barefoot,
23 Marlborough Road,
Southall, UB2 5LW

Barnet area
Mrs. V. A. Brooker,
6 Merrivale, Southgate,
London N14 4SH

Ealing area
Mr. L. R. Mower,
59 Betham Road,
Greenford, Middx.

North East (Forest) Area
Miss D. Baxter,
8 Keith Avenue,
Wickford, Essex.

LONDON SOUTH
Mrs. C. Byrne,
Flat 1, 10 Wexford Road,
London, S.W.12.

MANCHESTER AND DISTRICT
Mrs. E. Taplin,
Colonial House,
63 Corporation Street,
Manchester M4 3DT

MANSFIELD, WORKSOP AND DISTRICTS
Mrs. E. Freeman,
23 Melbourne Street,
Mansfield Woodhouse, Notts.

NORTH EAST (Northumberland)
Mrs. E. Grant,
27 Redwell Road, Prudhoe,
Northumberland.

NORTHAMPTONSHIRE
Mrs. Aldwinkle,
38 Robin Lane,
Wellingborough

NOTTINGHAM & DISTRICT
Mrs. S. E. Plant,
305 Foxhill Road,
Carlton, Nottingham.

PRESTON
Mrs. D. Snaylam,
72 Priory Lane,
Penwortham, Preston.

ST. HELEN'S & DISTRICT
Mrs. N. Maddocks,
324 Warrington Road,
Rainhill, Prescot L35 9JA

SALISBURY AND DISTRICT
Mrs. J. Renshaw,
195 Gainsborough Close,
Salisbury SP2 4HB

SHEFFIELD
Mr. T. Robinson.
4 Longford Close,
Bradway, Sheffield S17 4LH

SOUTHAMPTON & DISTRICT
Mrs. P. M. Trim,
20 Depedene Close,
Great Roman Way Estate,
Holbury, Southampton S04 IPQ

STAFFORDSHIRE
Mrs. J. Davies,
8 Oakhill Avenue,
Oakhill,
Stoke-on-Trent ST4 5JN

STAINES, HOUNSLOW AND DISTRICT
Mrs. C. Taylor,
3 Chester Avenue,
Twickenham.

STOCKPORT
Mrs. S. Silver,
1 Brookside Avenue
Offerton, Stockport.

SUNDERLAND
Mr. W. D. Easton,
4 Irene Avenue, Grangetown.
Sunderland.

SURREY (NASBAH)
Mrs. C. J. H. Phillips,
304 Croydon Road,
Wallington, Surrey.

SUSSEX
Mrs. Y. Barnes,
110 Penland Road,
Haywards Heath, Sx.

SWINDON AND DISTRICT
Mrs. J. Trembling,
3 Church Place,
Swindon, Wilts.

TRAFFORD
Mrs. A. Bough,
9 Overdale Crescent,
Flixton, Urmston.

WARRINGTON & DISTRICT
Mr. S. J. Charlton,
36 Park Avenue,
Latchford, Warrington.

WARWICKSHIRE
Mr. R. W. Chawner,
18 Finch Drive,
Sutton Coldfield, Warwickshire.

WESSEX
Mrs. N. V. Barnett
6 Icen Road,
Radipole, Weymouth.

WIRRAL
Mrs. S. Keeler,
7 Church Road,
Upton, Wirral.

WORCESTERSHIRE
Mrs. M. Davis,
Lower Field,
Wynniatts Way, Abberley.

YORKSHIRE NORTH
Miss F. M. Seward,
45 The Paddock,
York YO2 6AW

NORTHERN IRELAND BELFAST & DISTRICT
Mr. J. H. Blackwell,
132 Orangefield Cres.,
Belfast BT6 9GT

SCOTTISH ASSOCIATION
Mrs. G. McIntyre,
General Secretary,
190 Queensferry Road,
Edinburgh EH4 2BW

MID WALES & BORDER COUNTIES
Mrs. D. Brayne,
5 Woodcote Way,
Monkmoor, Shrewsbury, Salop.

NORTH WALES
Mrs. M. Messham,
47 Cherry Tree Road,
Bradley, Wrexham.

SOUTH WALES
Mrs. D. Cox,
28 Cromwell Road,
Bulwark,
Chepstow NP6 5AD

OTHER LOCAL ASSOCIATIONS

Blackpool & Fylde
Mr. L. F. Sharpe,
1 Broadfield Ave,
Poulton-Le-Fylde.

Cannock & Walsall
Mrs. W. Evans.
19 Drake Road,
Bloxwich, WS3 3LR.

Chester & District
Mrs. K. Jones,
19 Beech Hey Lane,
Willaston, Wirral.

Cheshire South
Miss S. M. Hurley,
Flat 11, Waverley Court,
Herdman St. Crewe.

Chesterfield
Mrs. K. M. Tomlinson,
56 Brooke Drive,
Brimington Common,
Chesterfield.

Consett & District
Mrs. M. Holmes,
30 Watling Street,
Leadgate, Co. Durham.

Dudley & Wolverhampton
Mr. B. Attwood,
1 Autumn Drive,
Lower Gornal, Dudley

Isle of Wight
Mr. D. J. S. Sprake,
Springfield, Town Lane
Chale Green, Ventnor.

Lunesdale (Lancaster)
Miss P. Crook,
Brananlor, Ball Lane
Caton, Lancaster.

Rochdale
Miss B. Ashworth,
22 Lowther Road,
Rochdale.

Spenborough (Yorks.)
Mr. H. Lodge,
38 George Street,
Cleckheaton, Yorks.

Teesside
Mr. J. Gray,
Marchesi Centre,
Tollesby Road, Middlesbrough.

Wigan & Chorley
Mr. J. A. Hughes,
20 Kennedy Close, Standish,
Nr. Wigan, Lancs.

NORTHERN IRELAND

Ballymena
Mrs. E. Kenny,
The Bungalow,
Teesham, Ballymena.

Lurgan & Portadown
Mr. P. A. Smyth,
Marymount,
North Circular Road,
Lurgan, Co. Armagh.

Mid-Ulster
Mr. J. R. Stafford,
26 Killymerron Park,
Dungannon, Co. Tyrone.

EIRE
Enquiries to:
Mrs. M. Kinsella,
66 Martello Hill, Carrick Estate,
Portmarnock, Co. Dublin.

Printed by David Green (Printers) Ltd, Kettering, Northamptonshire